

**INQUIRY INTO VOLUNTARY ASSISTED DYING
Tennant Creek Mob Aboriginal Corporation**

Mr DEPUTY CHAIR: Thank you for having us. I would like to acknowledge we are on this land and pay respect to elders past, present and emerging. Thank you for inviting us down here to hear from you guys. My name is Matthew Kerle, I am the Member for Blain and the Deputy Chair, acting for the Chair this morning.

Mr YOUNG: I am Dheran Young, the Member for Daly. I represent the communities of Wagait Beach, Dundee, Berry Springs, Daly River, all the way to Wadeye and down to Pine Creek. I am also a committee member here, and I am with the Labor Party.

Mrs CARLSON: I am the Member for Wanguri, Oly Carlson. I represent the suburbs of Leanyer, Wanguri, Muirhead, and the northern suburbs adjacent to the Royal Darwin Hospital and Casuarina shopping centre.

JOSEPHINE: I am Josephine Bethel, the youth program manager with the Mob.

KEISHA: I am Keisha, Manager for Youth Night Patrol.

Mr DEPUTY CHAIR: Just for the record, do you mind giving us a brief overview of Bush Mob before we get into the questions.

JOSEPHINE: We are the Tennant Creek Mob Aboriginal Corporation. We are not Bush Mob.

Mr DEPUTY CHAIR: Sorry.

JOSEPHINE: We run several programs, NDIS community connectors, so they are up on that board. That is just helping the department and Commonwealth connect with NDIS participants, [REDACTED]—it is really connecting them if they have planned changes. [REDACTED]—We are not a provider, we are just connectors, so if they are looking for somebody and they need to put them on the phone—[REDACTED]—Keisha and I help connect them with the department.

We have community youth diversion, so that is court ordered through the police and the courts for kids that have committed an offence. We do diversion to divert them away from crime.

We do our youth-focused night patrol, which Keisha manages. That is getting kids safely home after hours, off the streets. That runs from, 8.30 pm to 4 in the morning. We do youth night activities. Friday and Saturday nights, we do that. That can range from activities on site here—we do everything from bingo, cooking, body butters, whatever the kids like, and we run that from 6 pm to 10 pm and then we take the children home.

We do harm-minimisation activities, some of which we talked about on the poster there, where we do the soap making, going out on country, collecting oils and things for soaps, making the *yakula* with the ladies. We do suicide prevention, so we have done three lots of training—Jaq will be able to talk about that. And Jaq, you can talk to the Commonwealth psychosocial support, those last two.

[REDACTED]

[REDACTED]

JACQUELINE: [REDACTED]—I am the CEO of the corporation. The suicide prevention project [delivered by The Mob] is about training up first responders in communities to deal with suicides that happen on site. We have very limited mental health services in the region—[REDACTED] The referral pathways into services just aren't there in remote areas. What this project is about is training up community members in Mental Health First Aid so they can act as first responders in emergencies.

A lot of the communities in the region do not have permanent police, so when somebody commits suicide it is often the families that have to deal with it. [REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

As part of that, we developed a suite of suicide education language materials in Warumungu, Mudburra and Alyawarr, which are the three main languages between Elliott, the region and here.

The psychosocial support program is about assisting mental health participants, so it links in with the NDIS community connectors. We have lots of people with mental health disorders that are diagnosed and undiagnosed and have not been able to get onto the NDIS. A lot of those people are in remote communities. They don't have treatment services and are not on the NDIS scheme. This program is about working with that family to get them to a treating doctor, which is often difficult, and hopefully getting them assessed and into the NDIS scheme. And if they are not eligible for NDIS, providing that weekly base for them, doing activities here, say once a week, or just having a check-in and a place where they can come .

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

JOSEPHINE: And the youth education one under your suicide prevention.

JACQUELINE: As part of the suicide prevention project, we have also focused around the kids from 10 to about 18. We linked in with RN Employment, which has the CDP, and we also linked in with the National Wellbeing Alliance. What they have done is come in and actually train people in mental health first aid. For the kids, rather than suicide and mental health, they call it deadly thinking workshops. It is about improving the way they think about issues, and when they have a crisis not catastrophising, like most teenagers do. It is about linking them back to their culture and finding out where their strength is.

They are all little things, but they all make up that social and community sector work that is really important to grassroots people and keeping everyone safe.

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

Mr DEPUTY CHAIR: When the *Hansard* comes through, we can provide it to them and they can highlight any areas they would like to have redacted.

JACQUELINE: That would be helpful, thank you.

Mr DEPUTY CHAIR: Because things are being recorded, the ideal would be that—because this is a hearing with parliamentary privilege—we would like to make as much of the transcript public as possible, but obviously there are sensitive things to discuss, so for any of those we go *in camera*, we call it, and that bit does not go on the public record. We still have it for the report, so if there is a really interesting finding with a bit of information that we need to know that you can tell us, we still know about it but it does not go public on the website.

JACQUELINE: Absolutely, I get that.

Mr YOUNG: It will not go in the report, if it is meant to be redacted.

Mr DEPUTY CHAIR: It will help us. There might be things that are good for us to know in context.

Mrs CARLSON: Just so you know for today, we are here to talk about voluntary assisted dying, obviously.

Mr DEPUTY CHAIR: That is what I was just about to read.

Mrs CARLSON: I will let you go.

Mr DEPUTY CHAIR: We are here to talk about voluntary assisted dying, or V-A-D. That is the use of a prescribed substance to cause the death of a person who is terminally ill, at their own request. It is a process that gives an eligible person the choice to ask for medical help to end their life in the manner and time of their choosing. It is very important to be very clear that that is only for people who are—every other state and territory in Australia has legislated it. There was an expert report commissioned by the previous Labor government that was done by the Administrator and Duncan McConnel, one of the senior lawyers, and a panel of experts.

They produced the report, and our job—the Attorney-General wrote to us and said, ‘Can you please do an investigation with some terms of reference’, because there was concern that that report did not consult sufficiently in remote communities, and there are a few other things in there. So that is why we are here. The model around Australia that is emerging is that the person has to have a terminal illness, it has to be progressing, has to have intolerable suffering, and then there is a process where they have to see a few doctors to certify to that effect. They have to be of sound mind and voluntarily making the decision under no duress.

We are conscious that it is a very difficult topic and may be upsetting. Many of us deal with quite a lot of death and dying already, but if you—sometimes people need to take a break when we are having these discussions, so if you want to take a break at any time ...

JACQUELINE: That is okay. We are happy to discuss it. Look, the only other thing I would say about that is there is—does a power of attorney have capacity to make that decision?

Mr DEPUTY CHAIR: It has to be the person.

JACQUELINE: What if the person has a mental health illness.

Mr YOUNG: They are ineligible.

JACQUELINE: Ineligible? Dementia—ineligible? No way.

Mrs CARLSON: In some jurisdictions it is ineligible, and this is what we need to actually ...

JACQUELINE: Yeah. So can we talk to that?

Mr DEPUTY CHAIR: Yes, please, go for it.

Mr YOUNG: Before we do, just to clarify a few things, the report that was handed in last year in August mentioned—and then we have been asked again to come out and consult with mainly Aboriginal communities in remote and rural areas. Our role now is to produce another report from these consultations, which will go to the government. We are not here to legislate anything; we are here to provide a report to the new government. Then it will be up to the government if they go forward, to produce a Bill on voluntary assisted dying. This report will guide them; there will be drafting instructions put forward to the Attorney-General.

We are not here to legislate; we are here to provide a report. There will be recommendations ...

JACQUELINE: We understand the process.

Mr YOUNG: ... but we can talk to the previous report and what may be in this report as well.

JACQUELINE: We would say, from our perspective ...

CAROLINE: Sorry, can I just mention, with a mental illness, you have to have a terminal illness, but you may also have a mental illness, so you cannot discriminate on the basis on someone with a terminal illness having a mental illness. You can still access VAD. You cannot just have a mental illness and access VAD.

JACQUELINE: Where does Old Timers fit?

JOSEPHINE: No, it does not.

Mr DEPUTY CHAIR: No. If you, for example, had terminal cancer or renal failure and also had Alzheimer's, you could apply for VAD on the basis of the terminal illness, like the renal failure or cancer, but not the Alzheimer's.

CAROLINE: If you are still of sound mind.

Mrs CARLSON: You have to be of sound mind when you make the decision.

Mr DEPUTY CHAIR: And you have to be of sound mind when you make the decision.

JACQUELINE: So there is no process? Is there no process? We have an Early Onset Alzheimer's gene. These people are dying very young. They are 46; that is very young. They have had the illness for eight years, five to eight years.

Mr DEPUTY CHAIR: Early onset?

JOSEPHINE: Early onset Alzheimers. [REDACTED]

Because they are so young, surely when they have their faculties, when they are first diagnosed, they should be able to make that decision.

Mrs CARLSON: I think in a lot of jurisdictions at the moment, it is quite a sensitive disease. When that time comes, they do not have the capacity to make that decision, so, unfortunately, there is probably not a jurisdiction at the moment that really wants to—but having these conversations now, it could be something that needs to be looked at in the future, when we talk about advance personal plans. A lot of regulations and other legislation would have to be updated, but it is now the conversation we are having, and it is really good that you guys are.

JOSEPHINE: We need to have that conversation, because they are young.

JACQUELINE: Anyway, the point is, there needs to be a review point with that. There needs to be a review point to say that this does need to be included. Yes, at the beginning they can agree. At what point do doctors suggest that they are legally incapable of making that decision? And at what point do they get power of attorney permission to do that, and with the doctor's agreement? That needs to be reviewed. It is a major issue for people with early onset Alzheimer's, and we have seen it repeatedly in our family. [REDACTED]

JOSEPHINE: And it is for five weeks; it is not a slow process.

JACQUELINE: We have had to see that repeatedly. When you have a person with early onset, their organs are young, so obviously they will hold on a lot longer because of their young organs than a person who may have other conditions. But that needs to be reviewed. It is a really big omission. We understand the difficulties, but we believe that a bit more thought needs to be put into that rather than just putting it in the too-hard basket, particularly for early onset [Alzheimer's].

If you have a look at the data on that and the evidence base, what you find with a lot of people with early onset who are diagnosed young commit suicide because there is no assisted dying. Rather than having five years of good life with their children and grandchildren and families ...

JOSEPHINE: They kill themselves while they can remember.

JACQUELINE: ... they are choosing to take their own lives beforehand.

[REDACTED]

[REDACTED]

JACQUELINE: We have actually had that happen within our family, with one of our family members who was diagnosed. When he was diagnosed, he committed suicide. He made that decision because there was no legislation.

Mr DEPUTY CHAIR: Can I just be clear, when you say family members do you mean clients or your personal family?

JACQUELINE: We are talking about a direct family member that occurred to [REDACTED]. That is just one example that we can use [REDACTED]. But we are not the only family in Australia that has all that.

Mr DEPUTY CHAIR: This is really important because there has been some discussion about the inclusion of Alzheimer's and dementia. There is some wording around anticipation of suffering, the anticipation causes. If you can give us testimony about this issue, that would be really good.

JACQUELINE: Absolutely.

JOSEPHINE: Absolutely.

JACQUELINE: The thing about our family with the disease, which we are happy for you to use as part of this review is, we have been studied for, I think, 30 years or 40 years.

JOSEPHINE: Over 34 years. We are part of the Dian study.

[REDACTED]

[REDACTED]

JACQUELINE: We have family members from each part of the family who are dedicated as part of that trial each year, and we have done that so we can eliminate the gene in the next generation. We are not coming from a place of emotion or uninformed or uneducated on the topic; we are coming from a place of experience and a proactive place of putting in place procedures. It is unacceptable to not include Alzheimer's; we would not let a dog die like that, so that just cannot be a too-hard basket—you need to go back and review that and work out what that should look like. Form an ethics committee. Form a doctors' opinions committee. There is lots of advice and expertise around that topic.

JOSEPHINE: We are not saying, in our case, in our family, 'I've got the gene; I'll kill myself now.' We have looked after each one of them for eight years at a time. [REDACTED]

[REDACTED] But the end game for them, it is horrific.

JACQUELINE: [REDACTED]—I was power of attorney for one of our brothers, and his son rang me—I was in Darwin when he was dying—[REDACTED]

[REDACTED]

[REDACTED] All his son could hear was him gurgling. That is his last memory of his father. Why? Why, when they could have given him an injection.

[REDACTED]

[REDACTED]

JACQUELINE: Yeah. There has to be a review point. There are too many cases of Alzheimer's and early-onset Alzheimer's where that last period is extremely traumatic.

The other area we wanted to talk about was cancer. We see a lot of cancer patients who have other complications and whatnot. Renal failure is another one that we see a lot in the communities here. Same situation, where they need to—most of them have been on renal and have had cancer for many, many years. They need to have the right to choose. Some, obviously, will not take that option for cultural reasons; others will, regardless of whether they are Aboriginal or not.

Mr DEPUTY CHAIR: We have heard a lot of evidence in this area. Do you think if it was, as an option, withdrawing from treatment with pain relief rather than going down the VAD and taking a substance ...

Mrs CARLSON: I think what she is talking about—there is some eligibility requirement in some states to do with the prognosis. Obviously, it is either six months or 12 months, depending, so are you saying that someone can live with cancer for a very long time but still have to go through all of that, but do not want to do all that treatment and live past the 12 months, but would rather the option, if they have been diagnosed, that no matter what the timeframe is, they have the right to choose?

JACQUELINE: Yeah, and I think there are two points. I think there is one where they get to choose, 'When I get to this point, that can be my out point', or there can be, 'I can't tolerate the pain anymore'. That is what we hear a lot from cancer patients, where they say, 'I can't cope with the pain anymore'. The pain relief is not enough for them. They have had the injections and the immunotherapy. They cannot cope with the pain anymore. They are not eating for weeks on end, and then they are propped up with a few vitamins and IVs, and then they go again for another few weeks. Nobody wants to see that, and neither do they want to go through that. It is the pain factor that is unbearable for them.

Mr DEPUTY CHAIR: We have heard evidence that for cultural people—persistent evidence that cultural people would not be able to choose VAD for various reasons, but they do want to go back to country. Sometimes they talk about withdrawing from care and then having pain relief to manage it so that (inaudible).

JACQUELINE: Yeah. A lot of them.

Mr DEPUTY CHAIR: In the scenario you were talking about there, what would be a good option for those people?

JACQUELINE: Three different scenarios. One is the cultural care that you are talking about there, and that is an appropriate pathway, that would be our experience. The second one is people who are diagnosed with cancer and they know it is terminal, having an option then to say at what point they would like to exit. Some will not want to go to that end stage, [REDACTED]. And then you have the end stage. There are three different parts to it.

The end stage is where they have been through all the treatments, they are stage IV, final, no further options, and in significant amounts of pain that they cannot cope with, and their only other option is to take their own life, whether it be with medication or other means.

[REDACTED]

JOSEPHINE: They often stop treatment. They say, 'I've had enough. I'm not going to do it anymore.'

JACQUELINE: But they should not have to suffer through that. That can still be their choice, but there's three prongs to that.

Mrs CARLSON: With the number of suicide scenarios here, there is obviously what the report was proposing was a centralised model that obviously we would, because of the vast distances and remoteness of some of these places—sorry, the prescribed drugs that will be used for the voluntary assisted dying, that probably then would not be able to be stored here, because you could have instances that use that—would you say that is a safe—I am trying to ask what are some safeguards for the community with those types of medications?

Mr YOUNG: Do you mean storing ...

Mr DEPUTY CHAIR: Do you mean at the clinic or out there?

Mrs CARLSON: Anywhere. Like these ladies (inaudible).

JACQUELINE: You would have thought that in the centres like Tennant Creek, which is a regional town, the hospital would have facilities to store that. Through NT Health and whatnot, they have remote teams that travel out that would be aware of the treatment plans for those clients. I think what it missing, in my view, is having some sort of regional ethics committee—I do not know how the other states are structured—just so it takes the onus off the medical teams.

What the family wants at that time—let us say if I say, 'I want to die; all my family agrees,' having that regional ethics committee to say yes.

[REDACTED]

JACQUELINE: And also to take the onus off the doctors. [REDACTED] We do not want, in our view, any of that coming back on doctors or medical staff to put them in a position where they may be sued for making the wrong decision. Having a local ethics group that says, 'Yeah, we're all aware of everybody in the region. We know who's sick. We know that person has been suffering for a long time, and the family has made that decision; we know it's with the person's consent, and we agree that it is time to administer.'

JOSEPHINE: And it's hard on our hospital. We have been through it with our hospital. When one of our family members was dying, they did not have the staff or the resources to manage that at the local hospital. We actually moved into the hospital in the wing with him and stayed in the hospital and did everything needed to be done.

JACQUELINE: And a lot of families do that.

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

Mrs CARLSON: So then, do you think—a model is a centralised model, so these would be specific teams that only deal with VAD. They probably do other parts because of our unique setup with the Northern Territory. People do multiple jobs and wear multiple hats, but that is then a separated doctor from this community so that—and there is a separated nurse there as well. Those types of medical people—would that be a better model for ...

JACQUELINE: Absolutely. And, you know, as part of that local authority, yes, they are elected as part of council, but generally those groups are—in the remote areas—the cultural advisers for those regions. Being able to talk to them and say, ‘Who should this be? Should it be an extension of that or should it be made up of—who are the elders and who is the right person to liaise?’

[REDACTED]

[REDACTED]

[REDACTED]

Mr DEPUTY CHAIR: What I was going to say before—we heard, not just in the context of VAD, but in the context you were talking about where, say, there is a clash between Western understand of health information and cultural health information. In the Western sense, only the next of kin and the patient—the health information is shared with them. Whereas in a cultural sense, it is normally shared more broadly so there is kinship decision-making.

JOSEPHINE: That is right.

Mr DEPUTY CHAIR: And that is something that would need to be taken into account, were VAD to be made available or considered in a cultural context. One of the things in the report last year—they talked about having a centralised service, so people would fly out from Darwin and you would have a handful who would only do that. But the trouble is, we do not have enough doctors and nurses right now to deliver healthcare to the living, to people who want to live, so what we have been looking towards is, when you are talking about a cultural person wanting to engage with VAD, the people involved have to be from somewhere else.

JOSEPHINE: Yeah, 100%.

Mr DEPUTY CHAIR: No possible comeback on any of the local health staff. So it is someone who is not connected at all, and there would have to be some consideration to the cultural decision-making if it was a cultural person. There is a clash there, because in Western ways of thinking, it is an individual decision, and it will be challenging to translate that into kinship decision-making as occurs in a cultural setting.

JACQUELINE: Yeah, look, there needs to be further discussion around that with groups of cultural elders. There are cultural law groups here throughout the whole region that would be able to provide direct advice on that. I think that there are enough cultural people to be able to inform that—and whether that is a real issue for this legislation or not. In terms of the legislation, it has to be treated as an individual decision, irrespective of whether they are a cultural person or not. If they make that decision, this is the process. All that would need to happen is there would need to be a few extra steps in the process for them to be able to communicate that within their cultural group. That responsibility would have to sit with them, because you have too many cultural groups here, but if you are a cultural person, and if you choose this option rather than going down the cultural line, the responsibility has to sit on the individual in terms of legislation.

Mr DEPUTY CHAIR: I have a question about safety, but I need to touch on the model a bit so you understand. The model we are looking at—the Australian model—involves two doctors signing—so the person has that terminal diagnosis that is progressing and there is suffering, and they make a decision that they want to access VAD. So then they need two doctors, and we are trying to figure out whether one is a specialist or both GPs—but they need two doctors to sign off, and they need written authorisation. The doctors have to say they are of sound mind, it is a voluntary decision, they are not under any coercion, tick the medical boxes of terminal and progressing and intolerable suffering, and then the fourth stage is the administration of the substance. There is self-administration or—now, the question would be ...

JACQUELINE: Where is the family in that? Where is the next of kin?

Mr DEPUTY CHAIR: The person would be responsible for communicating that to the family. The Australian model is designed—I say Australian because all the other states and territories have legislated, and if you draw a line through them, that is called the Australian model. It is a very individual process. It is based on the individual's wishes. We have heard stories where a person may be choosing VAD and not wanting to tell their family because there is too much hassle there. The question I wanted to ask is, in that model where, say, we do not want to entangle any local health staff in VAD—so when someone flies in to do the administration, could those first two doctors be local and that be kept—or would that be too close to the process and they might get blamed?

JACQUELINE: Look, I think that the local doctor would have to recommend it, because they are the ones that treat them.

JOSEPHINE: And working with that patient all the time.

JACQUELINE: Yeah, so they would have to make the recommendation to the VAD team, and then the VAD team would have to sign off on it. [REDACTED]

CAROLINE: With the death certificate in most jurisdictions, it is not recorded as a VAD death. That is part of this, to try to remove the stigma associated with VAD. It would be death as a result of the underlying condition, so it is not recorded as a VAD death. It is in terms of the statistics and the report produced by the review board on who is using the service, but it will not, generally, be on the formal death certificate—in other Australian jurisdictions.

Mr DEPUTY CHAIR: It would be whatever their terminal illness was, like renal failure, cancer.

JACQUELINE: Our view would probably be that it would have to be recommended by the local doctor because they are the treating doctor. They would know enough about the patient on a day-to-day level.

Mr DEPUTY CHAIR: Would it be enough if they just referred them?

JACQUELINE: Yeah.

[REDACTED]

[REDACTED]

Mr DEPUTY CHAIR: So there is a whole discussion in last year's report and there will be stuff in our report about doctors who can conscientiously object. In order for a doctor to engage with VAD and be one of the two signatories, they will have to go and basically be VAD certified. There is a whole process there of what they get certified as. Local staff could all conscientiously object, but then if someone brought it up—or they could be free to suggest it if they felt it is appropriate, and then refer them to someone they know elsewhere who is able to offer that service. Then the challenge would be the geography of contacting them.

JACQUELINE: In relation to not being recorded as VAD, what happens with superannuation and all of that? Is it built into the legislation that they cannot discriminate? Is it considered an assisted death, is it suicide, or like ...

CAROLINE: It is not regarded as a suicide. It is not.

Mrs CARLSON: I can speak a bit about that.

JACQUELINE: I was just thinking of superannuation.

Mrs CARLSON: I spent 25 years in superannuation; I have filled many death claims. When the death certificate comes, on what Caroline just said, as long as the death certificate says terminally ill, natural causes, whatever ...

JACQUELINE: The main condition.

Mrs CARLSON: Yes. This is something that, going forward, sometimes maybe the timeline could be for someone who is wanting to claim their superannuation earlier than their death, so you do have to have a doctor ask—two doctors to sign off, and one must be a specialist in the field that you are terminally ill with. You could potentially claim your death benefit and superannuation before. Not very many do that before, but it is something that—life insurances, things like that, you can actually claim before the actual event happens. This will be quite significant when it comes to those, but yes, the death certificate will reflect the (inaudible).

[REDACTED]

[REDACTED]

[REDACTED]

JACQUELINE: [REDACTED] There are a lot of our kids in our communities that are going to have major mental health issues into adulthood because of mental health conditions. What consideration has been given to them in this legislation? Obviously, by the time this comes in they will be in that age group where they are most susceptible to suicide, which is generally the 18 to 30 age group. Has there been any consideration for that group?

Mrs CARLSON: With the 2024 report, that was considered, but as part of the eligibility it is not part of the criteria. It is down to the terminally ill, intolerable suffering, things like that.

JOSEPHINE: And it is not age based, is what you are saying?

Mr DEPUTY CHAIR: There is a minimum of 18.

Mrs CARLSON: There is a minimum age 18. We are here to look into that report and then obviously supplement it.

JACQUELINE: Because we would argue that mental health is intolerable suffering.

Mrs CARLSON: If we go down that line, then we are moving away from the recommendations in that report.

JACQUELINE: Yeah, we do not care about that report. We care about the people in our community and where they are going to be in 10 years with these conditions. [REDACTED]

[REDACTED]

[REDACTED]

Mrs CARLSON: This is what I am saying, we are using the report as a basis ...

JACQUELINE: As a base, yeah.

Mrs CARLSON: We have the advantage that we are the last jurisdiction, even though we were the first, and the Territory is a unique place, so we have these other underlying things to consider, but at least now we are also, in today's conversation, considering possibly other options that need to be considered going forward.

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

JACQUELINE: With the NT population, the proportion of kids that are coming through with this autism, FASD, and all the others, where will that leave us in 10 years, that is what we need to plan for with this—and say what happens with this particular group and what provisions can be put in place within that legislation for them, if any? And who can make that decision on their behalf, because there are periods where they are perfectly of sound mind.

[REDACTED]

Mr DEPUTY CHAIR: Thank you. That is the first testimony we have had in that area.

[REDACTED]

[REDACTED]

[REDACTED]

Mr DEPUTY CHAIR: It is good to have the conversation.

Mrs CARLSON: Obviously being the last now, some of the ones that started earlier are probably thinking of things that are not working. It is being reviewed.

JACQUELINE: We do not mean to be rude about the report or your recommendations. What we are saying is that this is what is important to us in our community, and that is what we are providing feedback on.

Mr YOUNG: This is to add to the previous report, so that is fine.

[REDACTED]

Mr DEPUTY CHAIR: For the record, based on the testimony today, I think we should, as a committee, discuss making a recommendation in the report that there be a review post-implementation at a suitable period that would consider the topics we have discussed today.

JACQUELINE: Absolutely.

CAROLINE: And actually specify them in terms of that first review point, whether it is in three years—the scope of the legislation. It might be that is where dementia sits, Alzheimer’s and mental health.

JOSEPHINE: The dementia is an important one because the only option to them at present, with ours with early onset, is a DNR—do not resuscitate. That is their only option.

[REDACTED]

JOSEPHINE: And it is a long—that dying, it is too long. They should be able to, when they have their faculties still at the beginning, when they are doing their legal wills and all that, you know, on their diagnosis, they should then be able to do their VAD and say, ‘My sister, who is my power of attorney, can say when to call it’. You know what I mean? It is still their decision. [REDACTED]

[REDACTED]

JACQUELINE: We were very young women when the last VAD legislation came through in the Territory.

Mr DEPUTY CHAIR: 1995.

JACQUELINE: Yeah, and we had this conversation then. So you can put that on the record, that 30 years later we are back here having this same conversation. The last conversation that we were having was about our mother and our aunties having the same illness. [REDACTED]

[REDACTED]

Mr DEPUTY CHAIR: It has been 30 years, and it is time to just get it done.

JACQUELINE: Yeah.

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

Mr DEPUTY CHAIR: When is the cutoff for our written submissions?

Mrs CARLSON: Tomorrow.

[REDACTED]

[REDACTED]

Mr DEPUTY CHAIR: If you want to make an additional—we have written submissions via email open until tomorrow afternoon, so this is really good, but the written submissions will get published on the website and are visible to everyone. So if you want to put in a written submission advocating ...

JACQUELINE: To say we were here doing this same thing 30 years ago.

Mr DEPUTY CHAIR: Yes. You can just forward an email.

JACQUELINE: Forty—it was longer than 40.

Mr DEPUTY CHAIR: Is there anything else you would like to put on the record.

JACQUELINE: No, we just want to say thank you to you guys for the important work you are doing, and we really appreciate it.

Mr DEPUTY CHAIR: Thank you so much. This is a new data point. We have not had testimony like yours in pretty much the whole ...

Mrs CARLSON: We have had written submissions.

Mr DEPUTY CHAIR: Written submissions, but not people talking to us about it, so I really appreciate that.

JACQUELINE: Well, we are only one family [REDACTED]—but we need to be heard in this legislation. We will not be here in 30 years to come back for another round.

[REDACTED]

[REDACTED]

Committee concluded.
